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ABSTRACT

A review of the literature and a bibliography are provided on employment and the quality of adult life for individuals with disabilities. The literature review examines the concept of quality of life in general as well as quality of life assessments among populations with specific handicapping conditions. This is followed by a list of over 800 references to publications on quality of life. Journal articles, dissertations, and manuscripts are emphasized more than books, and supporting and peripheral publications are emphasized more than traditional, more visible works. The list is categorized using a specially developed coding system, which organizes citations by their degree of relationship to quality indicators of the population at risk, by their focus on quality of life or quality of working life, and by the special population targeted. The bibliographic citations are also listed in alphabetical order by author. Each citation contains the author, title, publication date, and the name of the journal or publisher. (JDD)

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Education Transition Center

Program, Curriculum, and Training Unit
California State Department of Education
Special Education Division
Sacramento, California

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Quality Adult Life and Employment:

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QUALITY OF LIFE:
REVIEW OF THE LITERATURE

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DAVID QUINN

This review is divided into two sections. The first will examine the literary treatment of quality of life as a general area. The second will focus on its impact among specific populations.

1. Quality of Life as a General Issue.

Quality of life is a concept which resists a unified characterization. It has been approached, variously, as a collection of subjective and objective elements (Schalock, 1987), as a consequence of resource availability (McCall, 1975), in terms of components of psycghological well-being (Flanagan, 1978) or personal satisfaction (Heal & Chasey Rusch, 1985).

Schalock's division of quality of life into subjective and objective components is an important assessment of different ways of operationalizing this concept. Under subjective components, Schalock lists psychological well-being and personal satisfaction. Following Flanagan's description of psychological well-being, Wehman cites such elements as physical and material well-being, inter-personal relationships, social, community and civic activities, personal development and fullfillment, and recreation. Personal satisfaction includes such variables as degree of satisfaction with residence,, community environment, friends, and time utilization. Objective measures cited by Schalock include mobility, appearance, physical condition, activity level and community involvement (Brown, Diller, Gordon, Fordyce, & Jacobs, 1984, as cited in Schalock, 1987). Additionally, it is suggested that quality of community life be operationalized in terms of degree of environmental control, amount of social interaction, and variety of community utilization (Kieth, Schalock & Hoffman, 1986, as cited in Wehman, 1987).

An additional complexity in evaluating quality of life was identified by Bradburn (1969) in his study of objective and subjective components of quality of life as determined by self-report. Subjective and objective elements were found to vary independently of each other.

II. Impact of Quality of Life Among Specific Populations.

In a study of 118 chronically mentally ill clients (in community placement) receiving services from New York State's Community Support System, Baker and Intagliata (1982) evaluated the quality of life (QOL) of these individuals in terms of The Satisfaction with Life Domains Scale (Andrews & Withey, 1976). The SLDS requires respondents to evaluate 15 life domains in terms of a "faces" format. That is, the seven point scale ranges from a "delighted" face with an upturned smile to a "terrible" face with a frown. Life domains evaluated include place of residence, neighborhood, diet, clothing, friendship and family patterns, work, leisure activities, economic situation, etc.

As expected, clients indicated the least amount of satisfaction with their economic situations, leisure time and health and greatest amount of satisfaction with community placement as opposed to confinement in a state hospital. This factor led to identification of a "grateful testimony" effect, meaning that degree of satisfaction with outplacement greatly colored the perceptions of clients concerning their actual life situation.In an attempt to measure the subjective well-being of chronically ill patients (Gill, 1984), sought an instrument that would not (as is usually the case) err on the side of impressionism or coarse objectivity. In a study of chemotherapy patients in a New Zealand hospital Gill devised an instrument which collapses 50 adjectives designed to measure current mood states of patients into three categories ("happiness" adjectives, "energy adjectives, and thinking or "distractor" adjectives added to prevent the formation of response sets). Results indicated that this tool is useful for clinicians attempting to assess the subjective well-being of patients as an aid in determining alternative treatments based on patient self-report.

Other applications of the concept of quality of life in medical settings include the work of Baird, Adams, Ausman & Diaz (1985) and Evans, Manninen, Garrison, Hart, Blagg, Gutman, Hull & Lowrie (1985). Baird, et al, sought to determine (with respect to cerebral revascularization patients) the relative contributions of global measures of neurological impairment to self-reported quality of life, the effects of medical risk factors related to strokes, and the relationship of neurobehavioral data to duration of symptoms of cerebral ischemia.

Self-reported quality of life was measured by use of the Sickness Impact Percent which consists of 139 statements which measure health status and treatment outcomes. Patients are asked to respond positively or negatively to descriptions of behavioral dysfunction in 12 domains of living: Ambulation, Mobility, Body Care and Movement, Social Interaction, Communication, Alertness Behavior, Emotional Behavior, Sleep and Rest, Eating, Work, Home Management, and Recreation and Pastimes.

Patient symptoms, based on an interview with a neuropsychologist, were divided into three categories: transient ischemic attack (TIA), reversible ischemic neurological deficit (RIND), or stroke. Symptomatic episodes lasting longer then 3 weeks were classified as a stroke.

Neurobehavioral impairment was determined by compilation of Average Impairment Rating, an arithemtic means of ratings on the Tokens Test, the WAIS Digit Symbol Test, Trail Making Test, the Sensory-Perceptual Exam, Grip Strength Test, Finger Tapping Test, Static Steadiness Test, and Foot

Tapping Test. This battery is designed to measure different patterns of cognitive-perceptual-motor dysfunction that may follow a stroke.

It was found that although the globel impairment rating was related to medical risk factors and duration of ischemic episodes, symptom duration of stroke-related medical factors were more strongly related to quality of life measure than the neurobehavioral summary score.

R. W. Evans (1985), in a survey of 859 patients undergoing dialysis or transplantation with respect to end-stage renal disease, sought to determine whether objective or subjective measures of quality of life were influenced by case mix (patient characteristics) or treatment. Quality of life measures included sociodemographic variables, age, sex, race and religion, subjective and objective measures, primary diagnosis, comorbidity (presence of two or more pathological conditions.), length of time on current treatment, and presence or absence of history of failed transplantation. Two subjective indicators, functional impairment and ability to maintain gainful employment, and subjective indicators measured by the Index of Psychological Affect, the Index of Overall Life Satisfaction, and the Index of Well-being, were utilized as measures of quality of life.

It was found that transplant patients enjoyed a higher quality of life than dialysis patients on three subjective measures (life satisfaction, well-being, and psychological effect). Additionally, dialysis patients were not able to work or function at the same level as people in the general population.

With respect to the impact of the concept of quality of life on other populations, Gillman, Simmel, and Simon (1986) described the effect of visual impairment on elderly public housing residents. Previously, clinicians and other service providers had documented the difficulties experienced by this population. However, prior to the Gillman study, little data existed concerning elderly visually impaired persons failing to seek help from clinicians or social agenc[illegible].

Subjects included participants in EASYRIDE, a transportation program for elderly and handicapped residents of the Lower East Side of New York City sponsored by the Vera Institute of Justice. In 1976, it began operating a small fleet of wheelchair-accessible vans as a door-to door transportation service. Four hundred eighty six seriously disabled residents over the age of 62 were selected for the study. Relevent categories of this study included visual impairment in demographic subgroups, visual impairment as a travel handicap, visual handicap and self-reported health, and visual handicap as related to well-being.

Visually impaired residents reported significantly more health and morale problems than individuals not reporting visual impairment. Additionally, they reported that their lives were more unpleasant, boring or worse than their friends and that they experienced feelings of isolation and uselessness. These findings cast doubt upon the conventional wisdom which suggests that social and psychological services needed by the elderly visually impaired are similiar to those of their non-impaired counterparts.

Reich and Zautra (1984) provide another approach to the relationship of quality of life to elderly individuals. Reich and Zautra utilize the concept of daily event causation to analyze quality of life variables from the vantage point of degree of control over daily life events. Four strands of literature are reviewed (retirement, death of a significant other, relocation and institutionalization) in the form of the following event sequence: causation of event, response to event, and outcome of event activity.

It becomes obvious that "Quality of Life" as a single concept can be and has been operationalized but due to its personal nature, concensus on the operational components, as of now, remains only an admirable goal. Even if some approximation of concensus did come about, the literature clearly outlines the perils of combining demographic and disabling condition variables. In other words, quality of life means different things to different people. At best, specific subgroups have more similarities than does the entire population.

It is clear that if one desires to measure the degree of or change in quality of life many diverse methods do exist - in that, lies both beauty and frustration.

DESCRIPTION OF CODING SCALE

PURPOSE:

The purpose of this guide is to allow the investigator to locate references of publications related to quality indicators with the greatest ease. Within this guide, journal articles, dissertations, and manuscripts are emphasized more than books. Likewise, this guide attends more to supporting and peripheral publications than it does the more traditional and visable works.

The questions; Does the article deal primarily with the at risk population?; Does it deal with quality of life, quality of work life, or both? and; Specifically to which population does the publication attend? are all areas which can be easily referenced with this guide.

CATEGORIES:

The publications are categorized by each of the three areas listed below. For example, if a publication is categorized with the code 2.1.3 one would know that this publication was Supporting, deals primarily with quality of life issues, and attends to the physical/health impaired population. Below is a specific list of these categories:

HOW TO USE THIS GUIDE:

This reference guide is best used to locate references specifically suited to the needs of an investigator. Let us say you wish to locate publications which attend to quality indicators in the work life of individuals with typical behavior. In this case you would look at the coding scale below and design a three digit code. Section "A" asks about the degree of relationship your desired publications have with quality indicators. Since you want the reference to deal primarily with quality indicators you choose "1" as your first digit. The second digit (under Section "B") would be a "2" since you wish to investigate work life. Finally, under Section "C", the third digit would be a "5" since you are looking for information related to the typical population.

Therefore, the three digit code would be 1.2.5. This specific code can be found on pages 23 through 25. These forty five publications should be directly related to your investigation.

In addition, you may wish to find citations by a particular author(s). To do this, begin with page 96 and find the author(s) under the alphabetic list.

CODING SCALE:

A) Degree of relationship of publication to "quality indicators of the at risk population."

1 = On Target - The reference deals primarily with the at risk population and quality indicators.

(Reference guide continued)

2 = Supporting - The reference deals with at least one important issue of quality indicators that may or may not be related to the at risk population.

3 = Peripheral - The reference deals with some issues relating to quality indicators which may indirectly effect the at risk population.

4 = Unrelated - The reference deals with issues of quality of life or quality of work life but does not appear to relate to or effect the at risk population.

5 = Unknown - The reference title appears to be related to quality of life, quality of work life, and/or the at risk population but the article was unavailable during the time of this study.

B) Subject matter of publication.

1 = Reference deals primarily with quality of life.

2 = Reference deals primarily with quality of work life.

3 = Reference deals with both areas.

4 = Reference deals with neither area but may be important to their understanding.

5 = Unsure of specific subject due to unavailability.

C) Type of population targeted in publication.

1 = Severe Developmental Disability - Profound, severe, and moderate mental retardation, autism, multiple disabilities.

2 = Learning Disability - Mild mental retardation, learning disabilities including lack of opportunity to learn.

3 = Physical/Health Impairment - Sensory, homebound, severe health impaired.

4 - Emotional/Mental Disturbance - Severely emotionally disturbed, mentally ill.

(Reference guide continued)

5 = Typical Population - No specific condition which socially impairs the population.

6 = Other At Risk - Non-English speaking, pregnant minors, incarcerated youth, economically disadvantaged, etc.

7 = Combination - Two or more unrelated disabilities. For example, this should be coded as A.B.7.2.3 if the group in the study is learning disabled and health impared.

FORMAT:

The guide will begin with all references under 1.1.1, then 1.1.2, then 1.1.3 to 5.5.7. Finally, all citations appear together in alphabetical order.

INCOMPLETE CITATIONS:

Some citations contained within this guide are incomplete. Rather than not include the citations the author decided to denote them by completing the reference with an asterisk (*). Hopefully, you may be able to locate the periodical regardless of the incomplete citation. Good luck.

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